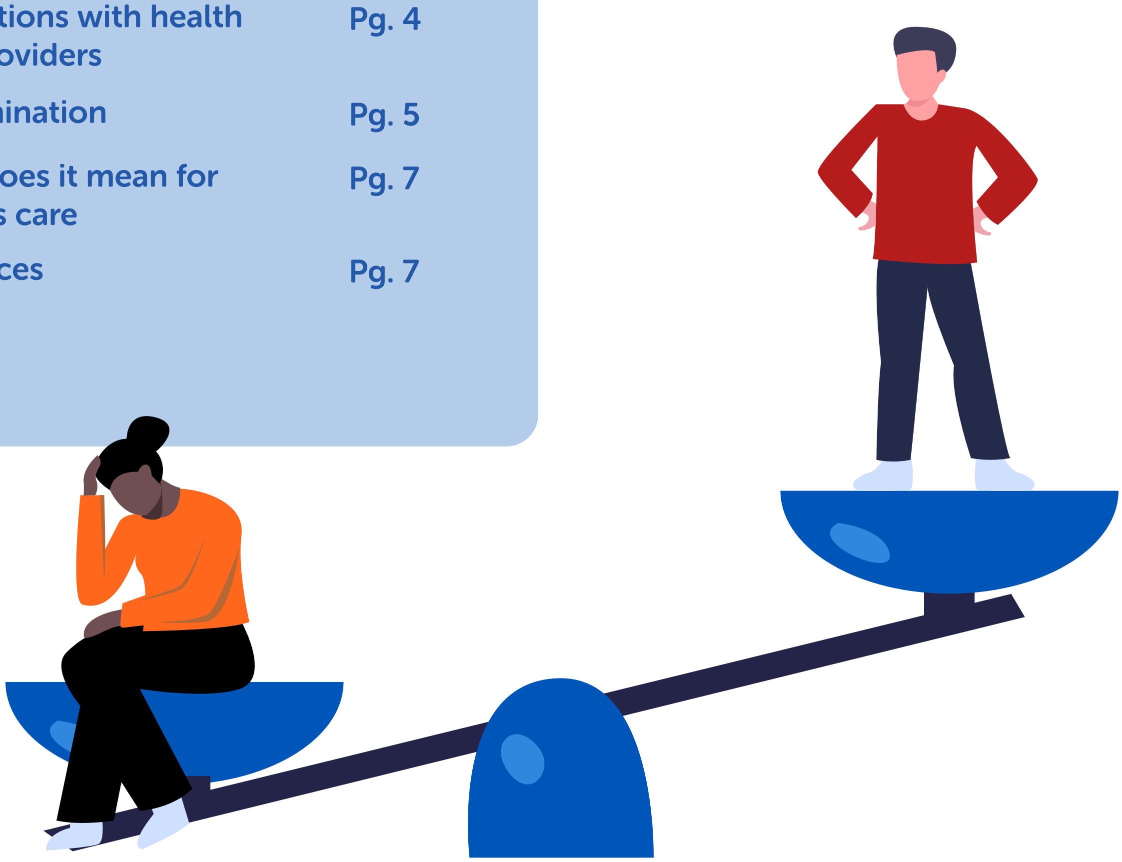
JointHealth™ insight
Arthritis research, education and advocacy news : November 2022

Arthritis Consumer Experts Survey Report on Arthritis and Health Inequities

Health inequities and disparities in Canada exist, are persistent, and in some cases, are growing. Many of these inequities are the results of individuals' and groups' relative social and economic disadvantages. Inequities in health outcomes or access to care can also be systemic where disparities are observable between population groups (for example, racial or ethnic).

In this issue of JointHealth™ insight

Arthritis Consumer Experts (ACE) is Canada's largest patient led arthritis group and is committed to understanding and raising awareness about inequities in arthritis care related to service delivery, treating, and managing arthritis, and self-advocacy. As part of that commitment, ACE recently conducted a national Survey to identify inequities relating to access to health care services between white and Black, Indigenous, and person of colour (BIPOC) respondents.



Background

Research has shown that BIPOC and underserved populations are at greater risk of having arthritis diseases, including rheumatoid arthritis, and experience higher disease activity than white populations[1, 2]. These differences do not occur by chance. Instead, they are the result of an interwoven combination of socioeconomic and cultural factors. Differences in access and treatment are rooted in a history of racism, discrimination, power imbalances, and cultural differences[3], especially for Indigenous Peoples[5]. A recent Canadian study that followed 7720 visible minorities and immigrants found that those who faced discrimination and unfair treatment were more likely to experience a decline in self-reported health status[5]. While the World Health Organization and federal and provincial governments in Canada have written reports and made calls-to-action[6], little has been done at the community, regional, and provincial levels to address health inequities in meaningful ways for Canadians.

How the Survey was conducted

ACE conducted a 33-question online Survey (Aug 2-19, 2022) in English and French. The Survey was conducted in partnership with Research Co., a public polling firm. Respondents answered questions regarding population characteristics, access to care, interactions with health care providers, unfavourable experiences, and information seeking habits.

Survey analysis

Survey analysis was conducted for three Survey groups:

- Black, Indigenous, and people of colour (BIPOC) respondents versus white respondents
- Rural respondents versus non-rural respondents
- Women respondents versus men respondents versus non-binary respondents

Who were the Survey respondents?

- A total of 1,249 responses were received.
- A quarter of respondents identified as BIPOC and three quarters of respondents identified as white.
- 3 in 5 respondents identified as women, 2 in 5 as men, and 1 in 100 as non-binary. Almost half of the Indigenous respondents identified as Two-spirited.
- 54% of respondents lived in urban areas; while 37% lived in suburban or rural areas.

Education and socioeconomic status

From our Survey responses, Indigenous peoples reported less formal education compared to white respondents. Black and people of colour reported similar levels of education as white respondents. Overall, no differences in income were observed between BIPOC and non-BIPOC respondents (Please note that individuals who complete online surveys tend to have higher indicators of socioeconomic status).*

Access to Care

Timely diagnosis and treatment for people with arthritis varies widely across Canada. Research shows that delays in accessing appropriate treatment and care can result in higher rates of disability, increased joint damage, increased pain, and significant reduction in quality of life.

ACE's Survey findings highlight the urgent need to address these health care needs and create equitable care. One in ten Survey respondent did not have access to a primary care provider. Survey respondents who were Black, Indigenous, or a person of colour, women, and individuals living in rural areas experienced disproportionate challenges in accessing health care:

- Compared to white respondents, BIPOC reported greater barriers to accessing care including time (40%), travel (31%), previous unpleasant experiences (21%), language (20%), and competing priorities (19%).
- Women reported greater barriers than men including travel (29% vs 19%), and previous unpleasant experiences (18% vs 10%).
- Respondents living in rural areas experienced even greater travel related barriers. Indigenous Peoples who resided in rural communities experience the greatest challenge.

Click to read what respondents told us >>>

*Please refer to the Addendum on page 8.

Access to Care

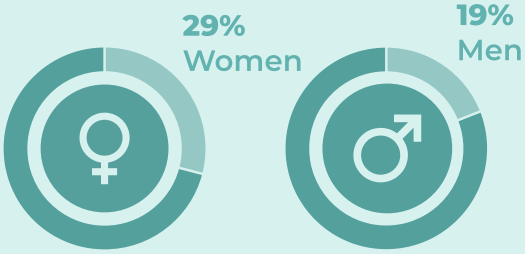
1 in 10 respondents
did not have access to a
primary care provider

Barriers to acessing care for BIPOC respondents

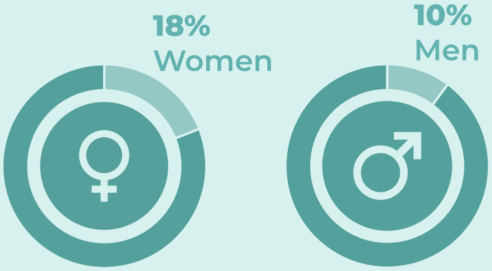
- Time
- Travel
- Previous unpleasant experiences
- Language
- Competing priorities

Barriers for men vs. women

Travel



Previous unpleasant experiences



Traditional medicines and practices

Medicinal plants have been used in traditional healthcare systems for centuries. A study published in the *Journal of Ethnobiology and Ethnomedicine* estimated that 70-80% of people worldwide rely on traditional herbal medicine to meet their primary health care needs[7]. Through trial and error over time, Indigenous Peoples have gained a vast knowledge of medicinal plants; this knowledge is passed down from generation to generation.

Our Survey asked if health care provider included traditional medicines and practices into their care and treatment recommendations. Amongst the Indigenous respondents, half said “yes” and half said “no”.

Click to read what respondents told us »»

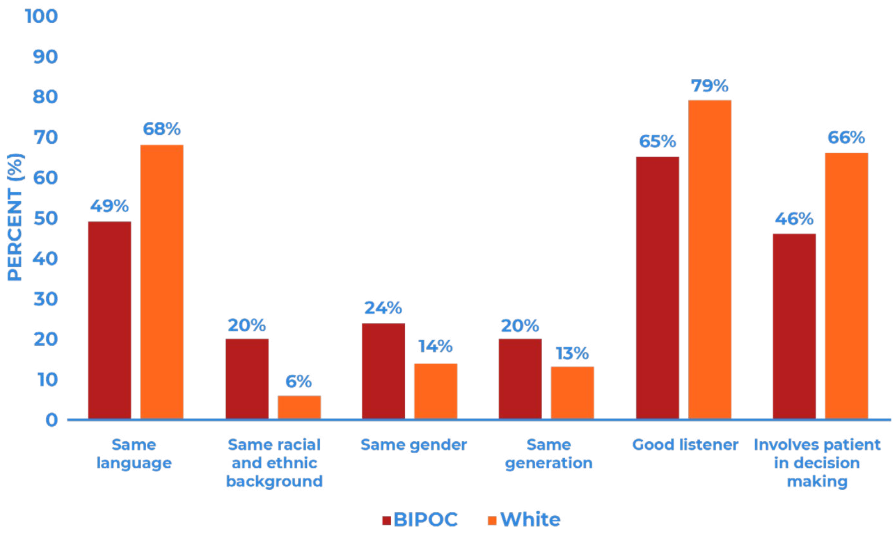
Interactions with health care providers

ACE’s Survey findings show that interactions with primary care providers were rated less favourable by BIPOC respondents. Results were even more pronounced when asked to rate interactions with a rheumatologist.

When asked which characteristics they looked for in health care providers (HCP), significant differences were revealed **[Figure A]**. BIPOC respondents reported favoring HCPs with the same racial background, gender, or generation. Good listening skills, involving the patient in decision making and speaking the same language were also valued by BIPOC respondents, but less by white respondents.

When compared to men, women rated interactions with primary care providers similarly, but rheumatologists less favourably. Eight in 10 women reported valuing good listening skills and 7 in 10 being involved in decision making, which is significantly more than men. The greatest differences occur in accessibility – 6 in 10 of women (vs half of men), and virtual care – 4 in 10 women (vs 2 in 10 of men).

Figure A: What characteristics patients seek in health care providers



Topics discussed with rheumatologist

When asked if they felt comfortable speaking to their rheumatologist about different topics, ACE's Survey found that:

- BIPOC respondents were less comfortable speaking with their rheumatologist about discomfort (29%) and medications (24%).
- Only one quarter of men reported being comfortable asking about discomfort (27%), and a third (35%) about pain, and a fifth about medication (21%). In addition, less than 16% of male respondents were comfortable speaking to rheumatologists about anxiety and depression.

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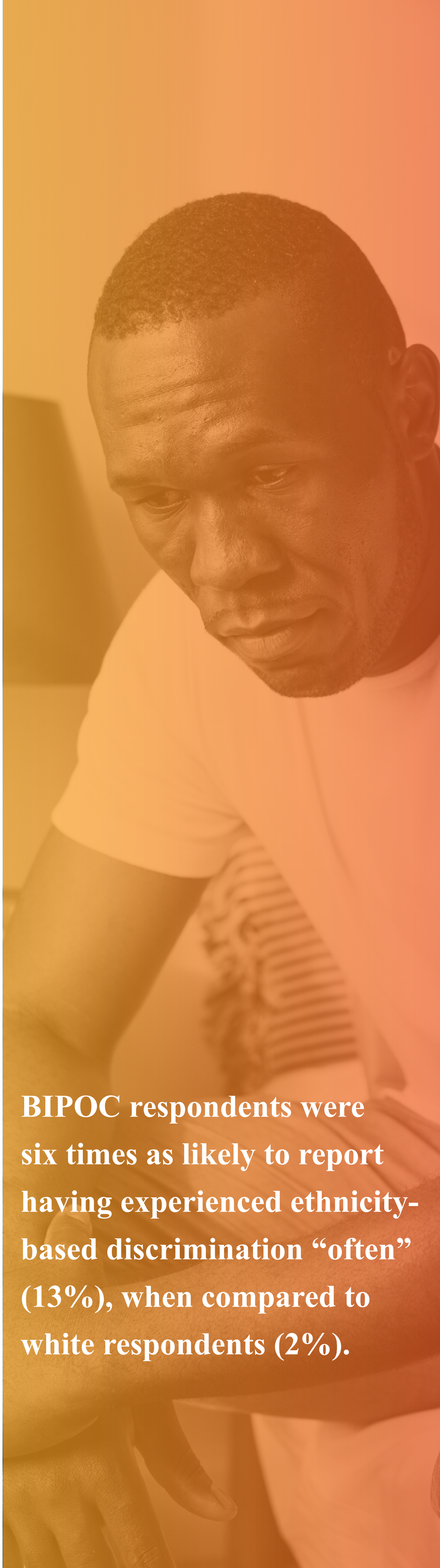
Discrimination

The Survey asked respondents how often they experience discrimination based on their race or ethnicity, gender, and sexual orientation. BIPOC respondents were six times as likely to report having experienced ethnicity-based discrimination "often" (13%), when compared to white respondents (2%).



BIPOC respondents were six times as likely to report having experienced ethnicity-based discrimination "often" (13%), when compared to white respondents (2%).

Results were even more pronounced for Indigenous Peoples who face discrimination "often" based on ethnicity (25% vs 2%), gender (21% vs 5%), and sexual orientation (15% vs 2%). Other findings include:

- Men reported experiencing discrimination based on race and ethnicity (7%), and sexual orientation (2%) twice as frequently than women (3% and 2% respectively).
- Women (8%) reported experiencing discrimination based on gender twice as often as men (4%).
- No differences were detected between rural and non-rural respondents.

Click to read what respondents told us >>>

Information seeking habits

Finding credible information about your type of arthritis is an important part to self-care and managing physical and psychological symptoms. Our Survey found that:

- BIPOC respondents more often turn to family, friends, coworkers, traditional healers, and elders for health information.
- Compared to men, women more often seek information from rheumatologists (38% vs 28%), others with a similar type of arthritis (29% vs 17%), patient organizations (18% vs 10%), and websites (72% vs 53%).
- Rural and non-rural respondents sought out information from similar sources.

When it comes to online information, the Survey asked respondents about indicators for trustworthy online resource and whether they feel that the information they find online is helpful. Survey findings include:

- Black (55%), Indigenous (54%) and POC (43%) respondents were more likely to find online information to be "helpful" and all preferred resources recommended by family and close friends with culturally sensitive content. In contrast to white respondents (66%), less BIPOC (51%) viewed official public health websites as trustworthy.
- Men and women found online information to be "helpful" (40% and 39%), but women preferred official public health sites and those run by health advocacy groups with a high-rank on search engines and have other indicators of credibility.

What does it mean for arthritis care

Our findings suggest that BIPOC respondents face significantly greater barriers when accessing arthritis care, and when they do, benefit less from their interactions. ACE's Survey results further reinforce current health literature that calls for training HCPs to create safe spaces, meaningfully address patient concerns and ensure the delivery of equitable care.

Resources to help build a culturally safe space:

- **Arthritis At Home: Equity and biases in rheumatology care with Dr. Diane Lacaille**
- **Arthritis At Home: Racism Against Indigenous Peoples in Alberta ER**
- **Cultivating Cultural Safety in Your Clinic: A Toolkit for Kootenay Boundary Practitioners**
- **Culturally Safe Care: Resources for health care workers**
- **Indigenous Engagement and Cultural Safety Guidebook: A Resources for Primary Care Networks**
- **First Nations Health Authority: Cultural Safety and Humility**
- **Assembly of First Nations It's Our Time Education Toolkit: Cultural Competency**
- **Saskatchewan Health Authority: Cultural Competency and Cultural Safety Toolkit**
- **First Nations and Métis Health: Cultural Competency and Safety Resource Centre**
- **San'yas Indigenous Cultural Safety Training Program**

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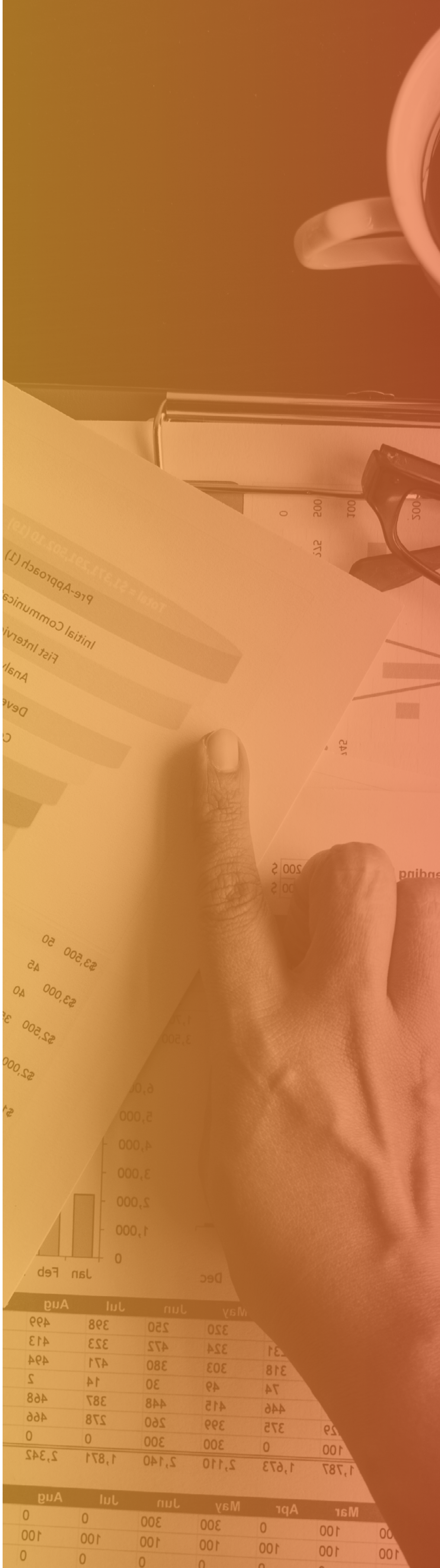
Addendum

Ethnic origin*	
East Asian	71 (6%)
European	772 (62%)
Latin American	49 (4%)
South Asian	55 (4%)
Southeast Asian	38 (3%)
Middle Eastern	32 (3%)
Other	153 (12%)

Education*	
Less than high school	47 (4%)
High school or equivalent	227 (18%)
Some college or university	292 (23%)
College or university graduate	572 (46%)
Socioeconomic status (Annual income)*	
$0.00-$19,999	112 (9%)
$20,000-$39,999	227 (18%)
$40,000-$59,999	195 (16%)
$60,000-$79,999	169 (14%)
$80,000-$99,999	120 (10%)
$100,000-$149,999	157 (13%)
$150,000 and over	87 (7%)
I prefer not to answer this question	71 (6%)

**Percentages do not add to 100% due to missing values and/or round off.*

Types of arthritis Survey respondents were diagnosed with	
Osteoarthritis	18%
Rheumatoid arthritis	15%
Ankylosing spondylitis	14%
Psoriatic arthritis	5%
Fibromyalgia	4%
Gout	3%
Adult-onset Still's disease	2%
Juvenile idiopathic arthritis	2%
Non-radiographic axial spondyloarthritis (not visible on X-ray)	2%
Lupus	1%
Polymyalgia rheumatica	1%
Scleroderma	1%
Sjögrens syndrome	1%
Vasculitis	1%
Do not know	26%
Other	5%



Arthritis Consumer Experts (ACE)

Who we are

Arthritis Consumer Experts (ACE) and its team members acknowledge that they gather and work on the traditional, ancestral and unceded territory of the Coast Salish peoples - xʷməθkʷəy̓əm (Musqueam), Sḵwx̱wú7mesh (Squamish), and Səl̓ílwətaʔ/Selilwitulh (Tsleil-Waututh) Nations.

ACE operates as a non-profit and provides free research based education and information to Canadians with arthritis. We help (em)power people living with all forms of arthritis to take control of their disease and to take action in healthcare and research decision making. ACE activities are guided by its members and led by people with arthritis, scientific and medical experts on the ACE Advisory Board. To learn more about ACE, visit **www.jointhealth.org**.

Guiding Principles

Healthcare is a human right. Those in healthcare, especially those who stand to gain from the ill health of others, have a moral responsibility to examine what they do, its long-term consequences and to ensure that all may benefit. The support of this should be shared by government, citizens, and non-profit and for-profit organizations. This is not only equitable, but is the best means to balance the influence of any specific constituency and a practical necessity. Any amount remaining from our annual budget at year end remains with ACE and is used to support the following year's core programs to continue helping Canadians living with arthritis.

For its past 20 years, ACE has consistently honored a commitment to its members and subscribers, academic and healthcare professional colleagues, collaborators, government and the public that its work is free from the influence of its funders.

To inform ACE employees and our stakeholders, members, subscribers that we will operate our organization with integrity and abide by the highest standards of lawful and ethical behaviour, ACE has adopted this strict set of guiding principles:

- ACE requests grants from private and public organizations to support its core program and plans and allocates those funds free from influence;
- ACE discloses all funding sources in all its activities;
- ACE does not promote any "brand", product or program on any of its materials or its website, or during any of its educational programs or activities.
- ACE employees do not receive equity interest or personal "in-kind" support of any kind from any health-related organization;
- ACE identifies the source of all materials or documents used;
- ACE develops positions on health policy, products or services in collaboration with people living with arthritis, academic research community, health care providers and governments free from concern or constraint of its funders or other organizations;ACE employees do not engage in personal activities with its funders;
- Cheryl Koehn does not own stock or any financial interest in any of its private or public funders.

Thanks

ACE thanks Arthritis Research Canada (ARC) for its scientific review of all ACE and JointHealth™ materials.

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Disclosures

Over the past 12 months, ACE received grants-in-aid from: Arthritis Research Canada, Amgen Canada, Canadian Biosimilars Forum, Canadian Institutes of Health Research, Canadian Rheumatology Association, Eli Lilly Canada, Fresenius Kabi Canada, Novartis Canada, Organon Canada, Pfizer Canada, Sandoz Canada, Teva Canada, UCB Canada, and the University of British Columbia.

Disclaimer

The material contained in this publication should not be relied on to suggest a course of treatment for a particular individual or as a substitute for consultation with qualified health professionals who are familiar with your individual medical needs. Please contact your physician for your own health care related questions.

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